Waiver Amendment

RIte Care Enrollment for Children With Special Health Care Needs

Rhode Island Department of Human Services
Division of Health Care Quality, Financing and Purchasing
Center for Child and Family Health

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1.0 STATEMENT OF PURPOSE

RIte Care, initiated in August 1994 under a Section 1115 Research and Demonstration Waiver (Project No. 11-W-004/1-01), is Rhode Island's Medicaid managed care program for low-income uninsured children, parents, and pregnant women. The implementation of RIte Care changed the nature of the delivery system for these Medicaid enrollees from a fee-for-service model to one that enrolls members in a Health Plan, provides every member with her or his own primary care physician, and incorporates standards for provider accessibility and responsiveness. A core goal was to increase access to appropriate, timely primary care and "sick visits," thus decreasing reliance on less appropriate emergency department visits and reducing avoidable hospitalization.

RIte Care has produced demonstrable results in increasing enrollee access to health care and improving health outcomes, while containing costs. Other studies of managed care programs have not consistently shown such improvements. RIte Care has several key design features specified in the RIte Care-participating Health Plan (Health Plan) contracts that are quite different from the Health Plans' commercial contracts. These design features, along with oversight and monitoring by the State, are key ingredients in RIte Care's success. Evaluations of RIte Care have shown very significant improvements in enrollees' access to timely primary care and specialty care. Choice has been expanded by offering access to a far wider network of primary and specialist care than has been available in fee-for-service Medicaid. In 2001, 98 percent of enrollees indicated that they are satisfied or very satisfied with RIte Care. Over the past six years, this percentage has increased from 95 percent in the initial survey.

RIte Care has been expanded incrementally over the years to include an increasing number of Rhode Islanders through eligibility expansions. This incremental approach has incorporated, for example, the State Child Health Insurance Program after the enactment of the Balanced Budget Act of 1997. This expansion included uninsured parents of children enrolled in RIte Care. In addition, State funds are now used to purchase coverage for family day care providers and their eligible dependents.

The Rhode Island Department of Human Services (DHS) seeks to build on this foundation to design and implement a service delivery strategy that will allow non-enrolled, Medicaid-eligible children with special health care needs to enroll in RIte Care and have their routine and specialized health care needs met through participating Health Plans. The State seeks to amend its existing Section 1115 Research and Demonstration Waiver to accomplish this goal. To leverage RIte Care's successes and strengths, increase accountability, provide focused oversight and monitoring, improve cost-effectiveness of health coverage, and integrate family coverage, the State seeks to enroll into RIte Care Health Plans children who: (1) are Medicaid eligible through receipt of Supplemental Security Income (SSI), the Katie Beckett Provision, or the adoption subsidy program, and (2) do not have primary health insurance coverage other than Medicaid. These children will receive the full RIte Care benefit package through a participating RIte Care Health Plan. Children who would otherwise be in the target population but who have commercial health insurance, Medicare, or CHAMPUS will be provided with Medicaid wrap-around services on a traditional fee-for-service basis.

The State has initiated and will continue to work with a broad range of stakeholders to inform and guide design and implementation.

2.0 INTRODUCTION

2.1 Children with Special Health Care Needs in Fee-For-Service Medicaid

As of December 2001, there were over 8,700 children with special health care needs in Rhode Island receiving health care services through traditional fee-for-service Medicaid. Almost 87 percent of these children are categorically eligible for Medicaid under the State Plan; 60 percent are SSI recipients and 27 percent are participants in Rhode Island's adoption subsidy program. The remaining 13 percent of the Medicaid-eligible children in fee-for-service qualified through the "Katie Beckett" provision

2.2 The Current Medicaid Fee-For-Service System For Children With Special Health Care Needs

The health care that Medicaid-eligible children with special health care needs receive on a fee-for-service basis is, by most measures, sufficient to meet the needs of the target population. However, a needs assessment, parent communications and advocate input have suggested ways in which substantial gains in the scope and quality of available services could be achieved by providing health coverage to children with special needs through RIte Care. Specifically, the State has identified three problem areas associated with coverage provided through traditional fee-for-service Medicaid:

(1) Fragmented Care. Fee-for-service Medicaid does not provide the level of care coordination required to respond fully to children with multiple and complex physical and behavioral health needs. Without this coordination, care is fragmented. The efficacy of treatment may be affected when providers are not aware of the range of services a child receives or needs or is doing without.

(2) Limited Choice and Access. A greater number of providers participate in RIte Care Health Plan networks than accept fee-for-service Medicaid clients. As a result, fee-for-service clients sometimes find it difficult to locate needed providers, particularly specialists, willing to accept Medicaid payment rates. Finding a provider often means making an appointment several months in advance of a visit. Limited choice of and access to providers is particularly problematic for the target population, given their complex and sometimes unique health care needs. Coverage through RIte Care Health Plans will ensure that children with special health care needs have both choice and access.

(3) Multiple Systems of Care. Forty percent of families with a child with special health care needs also have one or more children enrolled in RIte Care. These families must navigate multiple systems of care for their children. Enrolling siblings in the same service setting will simplify system navigation for many families in the target population.

2.2.1 Need for Greater Integration of Care

Children with special health care needs were not included in the original RIte Care Medicaid Section 1115 Demonstration Project for a variety of reasons. First, the State and consumers were concerned that managed care would be unable or unwilling to provide adequate services to children with special health care needs. Current research indicates that these concerns were unfounded, as fee-for-service Medicaid does not provide the same level of care management and care coordination available in the managed care system.[1] Children with special health care needs would benefit from a coordinated delivery system in which care is integrated, services are targeted to meet the needs of the individuals involved, and access standards assure timely service use.

Second, when RIte Care was first implemented in 1994, it would have been difficult to assure that the special needs of the children in the current target population were fully met. In 2002, RIte Care is a mature and successful program. Enrollment of the target population will build on the program's successes and will do so with focused attention on the special needs of the target population.

When needed services are not accessible, children often rely on emergency services, increasing preventable emergency department visits and hospitalizations. Accountability for access and coordination will improve children's ability to obtain the services they need to stabilize or improve their health. Although some degree of emergency service use can be expected for a population with high chronic health care needs, improved care management and access to ambulatory and specialty care will decrease the excess utilization of intensive services.

2.2.2 Provider Network Limitations

One of the ongoing concerns about fee-for-service Medicaid is its limited provider network. Medicaid reimbursement rates have not changed in a decade for most providers. This makes it difficult to find providers willing to take new Medicaid patients. In contrast, RIte Care Health Plans have more extensive networks – approximately 80 percent of Rhode Island providers participate in the Health Plans' networks. Prior to the development of RIte Care, children enrolled in Medicaid were only able to choose from 350 Medicaid-participating primary care and family practice physicians. The number of participating primary care providers tripled under RIte Care, greatly increasing the range of provider choices and access to services.

2.2.3 Need for Greater System Coordination

Under the current RIte Care waiver, Rhode Island has not been able to take advantage of the benefits of enrolling all family members in a single care system. Families with both children with special health care needs (as defined by the target population categories) and other Medicaid-eligible children must learn to negotiate two service systems – fee-for-service for the special needs child and RIte Care for the others. The Waiver Amendment seeks to reduce complications for families who currently negotiate multiple care systems simultaneously.

[1] Hill, I., et. al. *Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volume I: Synthesis of Study Results*, Health Systems Research, Inc. July 1999.

2.3 The Benefits of Enrolling Children with Special Care Needs into Managed Care Plans

By enrolling Medicaid-eligible children with special health care needs in managed care Health Plans on a mandatory basis, the State intends to contain the growth of costs for the target population. This programmatic change is incorporated into the State's budget for State Fiscal Year (SFY) 2003. The budget was developed in response to current year (SFY 2002) deficits and projections of sizable deficits for SFY 2003. The budget package includes calculations for the cost of covering the population in RIte Care Health Plans commencing on September 1, 2002, with full enrollment over the ensuing six months.

The waiver amendment's most significant opportunities and objectives are not financial. Central are the opportunities to enhance the quality of, access to, and coordination of care for children with special health care needs. The State plans to build on the existing RIte Care infrastructure using the currently participating Health Plans. Rhode Island has found that these Health Plans provide services efficiently and cost-effectively to Medicaid enrollees. The State will also draw on its experience in enrolling substitute care foster children into RIte Care.

RIte Care Health Plans currently enroll some children with special health care needs.[2] In Fiscal Year 2001, DHS enrolled children in foster care in a RIte Care Health Plan. This transition was implemented to better integrate medical and behavioral health care delivery systems for children in foster care by building on RIte Care's substantial strength in assuring access to comprehensive, quality services. The participating Health Plan strengthened the behavioral health provider network available to children in foster care, as all of the Department of Children, Youth and Families' (DCYF) active and specialty behavioral health providers were included in the Health Plan's network.

To date, children with special health care needs who are Medicaid eligible through SSI, Katie Beckett, or adoption subsidy have not had the opportunity to be included in RIte Care. The State believes these children can benefit from improved access to and coordination of care afforded through RIte Care, using a service delivery strategy that focuses on the child's unique needs, the strengths of the family, and coordination of services. This strategy expands provider availability, emphasizes quality, and ensures the timely provision of services. Slowing the rate of increases in costs is an anticipated byproduct of improved care.

Timely, consistent, coordinated, and accessible care helps children and families decrease the need for emergency services. Children with special health care needs have high rates of hospital admissions and often lengthy periods of stay. In 1999, the hospitalization rate was 233 per 1,000 enrollees for SSI and Katie Beckett children and 145 per 1,000 children for Foster Care children.[3] The average length of stay was 12 days for these children. Service improvements

[2] The Health Plans currently enroll RIte Care members who meet the medical criteria for SSI eligibility, but are not SSI eligible due to other factors. These children include non-citizen children who are in RIte Care (funded with State-only dollars) and children in families with income above the SSI income limit but within the allowed RIte Care limit.

[3] The data on Foster Care includes fee-for-service utilization for children in subsidized adoptive placements and children in temporary substitute care. The latter group was enrolled in RIte Care starting in 2000.

should help prevent unnecessary admissions and facilitate timely discharge to the home with appropriate community supports. For the general RIte Care population, the hospitalization rate dropped from approximately 150 admissions per 1,000 children before RIte Care began to less than 50 admissions per 1,000 children in 2001. The emergency department (ED) utilization rate for this population dropped from approximately 700 visits per 1,000 children before RIte Care began, to 300 visits per 1,000 children in 2001. Children with special health care needs could similarly benefit from a reduced need for emergency care when greater access to services is made available through RIte Care.

Some States enrolled all children in managed care at the outset, including those with special health care needs. Attention to children requiring more complex or specialized care suffered as a result. Rhode Island has taken a more incremental approach. This enrollment will draw on established RIte Care strengths and will be focused on the special needs of the targeted children. Amendments to the RIte Care Health Plan Contracts will incorporate specific provisions for children with special health care needs.

3.0 WAIVER AMENDMENT BODY

Following is the main body of Rhode Island's waiver amendment. This waiver amendment is guided by the January 19, 2001 "Dear State Medicaid Director" letter on children with special health care needs and the December 2000 *Review Criteria for Certain Children with Special Health Care Needs in Mandatory Capitated Managed Care Programs*. The format for this waiver amendment request follows the latter document.[4]

3.1 Public Process

In accordance with the May 3, 2002 Centers for Medicare and Medicaid Services (CMS) "Dear State Medicaid Director" letter, Rhode Island has provided and continues to provide significant opportunity for public input in the development and implementation of the waiver initiative. Based on its experience working with the RIte Care Consumer Advisory Committee, the Leadership Roundtable on Children with Special Health Care Needs, and the CEDARR (Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-evaluation) Policy Advisory Committee, DHS has, in the development of this Waiver Amendment Request, sought input from all groups that have an interest in children with special health care needs.

3.1.1 Stakeholder Meetings

Stakeholders interested in Medicaid-eligible children with special health care needs and their planned enrollment in RIte Care have been invited to participate in the community input, information, and implementation processes. Thirteen stakeholder meetings were scheduled over a four month period that began on March 15, 2002. The initial meeting was attended by approximately 125 individuals. The meetings, and the stakeholder process in general, have served three goals:

[4] The State also used the following document: Health Care Financing Administration. *Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs: Guidance for States Considering the Development of Medicaid Managed Care Programs for Persons with Special Health Care Needs*, October 1998.

- Sharing background and planning information with interested parties;
- Integrating feedback on the planned initiative as it developed; and
- Updating stakeholders about decisions, timelines and other processes.

Notice of the meetings has been (and continues to be) published in advance in *The Providence Journal*, the statewide newspaper with the greatest circulation. In addition, the following family advocacy organizations have notified their memberships of the public meeting schedule:

- Family Voices;
- Parents Support Network (PSN);
- Rhode Island Parent Information Network (RIPIN); and
- Paul V. Sherlock Center of Disabilities (formerly University Affiliated Programs).

The public meetings have been used to:

- Introduce the plan for mandatory enrollment of the target population of children with special health care needs in RIte Care participating Health Plans;

- Distribute "RIte Care for Children with Special Health Care Needs Fact Sheets";

- Distribute "Concept Paper For A Section 1115 Waiver Amendment For Enrolling Children With Special Care Needs In Rhode Island In RIte Care"; [5]

- Provide information on the RIte Care benefits package;

- Listen to participant concerns about and suggestions for how managed care for the target population might work best;

- Answer participant questions; and

- Obtain information on providers used by Medicaid-eligible children with special health care needs.

Information from the meetings has been used in other ways as well. For example, meeting participants provided the names of providers used by children in the target population, so that RIte Care Health Plans could use them for network development. The information distributed at the meetings was explained during the sessions, and meetings included time for participants to ask questions about the documents. The input from each public meeting has been used to refine the State's plans.

In addition to ensuring opportunities for participant questions and comments during each meeting, stakeholders were encouraged to submit questions, comments and suggestions in writing. Cards were distributed for this purpose during the meetings. The comments were read

[5] The concept paper was also shared with the Centers for Medicare and Medicaid Services (CMS), in order to obtain early guidance from CMS on the State's plans.

and organized by topic area in order to help DHS understand the topics about which participants needed information, the issues participants thought were most important, and other areas of concern to stakeholders. The comments, both written and verbal, were used to clarify issues and make changes to the Waiver Amendment's structure and target population (for example, stakeholder comments led to the decision to exclude children with primary commercial coverage from the target population).

3.1.2 Additional Stakeholders Input

Additional informational meetings have been held with advocacy groups, providers, State agencies, and the RIte Care participating Health Plans. Stakeholders targeted for involvement have included:

- **Beneficiary community** – Children and their parents, guardians, or adult caretakers;
- **Advocacy groups –** Individuals and organizations interested in children with special health care needs;
- **Related State agencies** – Department of Children, Youth and Families (DCYF), Department of Education (DOE), Department of Health (HEALTH), and Department of Mental Health, Retardation and Hospitals (DHMH), and the Rhode Island Public Transportation Authority (RIPTA);
- **Health service providers** – For example, physicians, hospitals, home health agencies, community mental health centers, and community health centers;
- **Professional associations** – For example, the Rhode Island Chapter of the American Academy of Pediatrics**;** and
- **Managed care organizations** -- Coordinated Health Partners (CHP, or Blue ChiP), Neighborhood Health Plan of Rhode Island (NHPRI), and United Healthcare of New England (UHCNE).[7]

3.1.3 Other Stakeholder Communication

The DHS web site was updated to include information on this proposed Waiver Amendment, including the Concept Paper, information on RIte Care and children with special health care needs, and meeting schedules and directions. Meeting participants were given the web site address and a contact e-mail address to which questions and comments can be submitted.

Letters and fact sheets were mailed to the parents, guardians, and adult caretakers of over 8,700 Medicaid-eligible children with special health care needs. The mailing provided an overview of the State's plans and a schedule of the public meetings. The letter was written in English and Spanish and included a telephone number to call with questions.[8]

[7] DHS continues to work with the Health Plans to develop this Waiver Amendment.

[8] The telephone line is staffed by the Rhode Island affiliate of the national family advocacy organization Family Voices. Family Voices provides information to callers in English and Spanish. The Spanish version of the letter

3.1.4 Ongoing Process for Public Input

As part of the rule-making process, notices will be published in *The Providence Journal* and several other media outlets, noting the period of public comment on draft rule changes. Written public comment will be taken for 30 days, and verbal comments will be permitted at the public hearing that will occur during this period.

Through the RIte Care Consumer Advisory Council and the CEDARR Policy Advisory Committee, the State will continue to seek input from stakeholders on the actual operation of the RIte Care Waiver Amendment for children with special health care needs. The RIte Care Health Plans attend RIte Care Consumer Advisory Council meetings and meet with DHS for regular implementation planning meetings. These activities will assure that the Health Plans receive stakeholder input and are themselves actively involved.

3.2 Definition of the Target Population

The following children with special health care needs are included in the population targeted for inclusion in RIte Care:[9]

- Blind/disabled children (eligible for Supplemental Security Income, or SSI, under Title XVI of the Social Security Act) up to age 21 (5,145 children as of December 2001).

- Children eligible under Section 1902(e)(3) of the Social Security Act ("Katie Beckett" children) up to age 18 (1,089 children as of December 2001).

- Children up to age 21 receiving subsidized adoption assistance (2,473 children as of December 2001).

The State plans to enroll into RIte Care only those members of the target population who have no other health insurance coverage. Preliminary analyses indicate that the majority of the children in the target population have no other health insurance coverage. Children who do have other health insurance coverage will continue in Medicaid fee-for-service, with Medicaid coverage to "wrap around" or supplement the other health insurance coverage.

At this time, the State does not plan to enroll into RIte Care: (1) children who live in institutional long term care facilities; and (2) children who currently participate in the Department of Mental Health, Retardation and Hospitals "Mentally Retarded, Developmental Disabilities" waiver program.

In addition, although not formally a part of this Waiver Amendment Request, the State plans to offer voluntary enrollment in RIte Care participating Health Plans to certain adults. This includes SSI-eligible adults whose children are already enrolled in RIte Care. The State believes that if parents and children are covered by the same health care delivery system, it will improve

indicated that a translation of the English-language fact sheet was available by calling the Family Voices telephone line.

[9] Foster care children have enrolled in RIte Care since November 1, 2000. As of March 31, 2002, 1,961 foster care children were enrolled in RIte Care.

access to needed health care for both parent and child, and will ultimately improve health outcomes.

Voluntary enrollment will also be available for individuals from the target population who would otherwise be disenrolled from RIte Care on their eighteenth birthday (for Katie Beckett children) or twenty-first birthday (for SSI and adoption subsidy children), as long as the individual retains her or his eligibility for Medicaid.

3.3 Identification and Enrollment

3.3.1 How Children with Special Health Care Needs Will Be Identified

The DHS will use Medicaid eligibility category in the current eligibility files to identify children for enrollment in RIte Care. As noted earlier (see Section 3.1), this has already been done for a point-in-time mailing to inform recipients of the State's plan for managed care and to invite them to participate in the public process. The culling of MMIS records will be repeated as the State moves towards its projected September 1, 2002 implementation date.

The DHS will be sending written communications to the families of children with special health care needs over the months prior to the enrollment into RIte Care of the first group of targeted children. Before the initial implementation on September 1, 2002, DHS will collect information on insurance coverage for those children for whom no insurance information exists in the Medicaid Management Information System (MMIS).

Children who become newly Medicaid eligible due to SSI, Katie Beckett or adoption subsidy, or who were previously Medicaid eligible who become newly eligible as an SSI, Katie Beckett, or adoption subsidy individual, will be identified on an ongoing basis as part of the eligibility determination process. These cases will be flagged by eligibility category for RIte Care enrollment.

3.3.2 Outreach Activities

Every affected individual has already received one mailing and will receive at least two additional mailings to alert her or him, and his family, guardian, or adult caretaker, of the required enrollment into managed care and how it will be accomplished. In addition, the public process has been and continues to be used to alert interested parties of the State's plans. The State also plans to use its MMIS contractor's provider relations function to apprise the provider community in a structured way of the State's plans.

3.3.3 Training Enrollment Staff and Other Relevant Parties

Within the months prior to implementation, State and contractor staff will systematically train the following individuals:

- DHS field workers
- DHS Info Line staff
- DCYF staff
- CEDARR Family Center staff
- Family Resource Counselors

- Covering Kids "helper site" staff
- Staff from family advocacy organizations

Training will focus on: (1) overview of the managed care system for children with special health care needs, (2) procedural requirements for selection of a Health Plan and a Primary Care Provider, (3) availability of materials for children and their parents, guardians, and adult caretakers, (4) frequently asked questions and answers, and (5) how to obtain additional information.

3.3.4 The Enrollment Process

The State plans to phase-in RIte Care enrollment for children in the target population over a six-month period. The enrollment activities are:

- Discontinuing disenrollments for children who are in RIte Care and who are new to the SSI, Katie Beckett or adoption subsidy eligibility group[10];

- Enrolling children with special health care needs who are currently Medicaid eligible through the SSI, Katie Beckett and adoption subsidy categories and who receive services through the fee-for-service system; and[11]

- Enrolling children who are newly eligible for Medicaid due to SSI, Katie Beckett or adoption subsidy.

The largest of the three activities will be the enrollment of the close to 5,000 children who are currently in fee-for-service Medicaid and who do not have commercial insurance. The DHS will enroll these children by geographic area. Utilizing this strategy allows DHS to concentrate its efforts, having more information sessions at multiple times and locations within a region, rather than spreading efforts across the entire state at once.

Individuals residing in areas outside the areas targeted in a given month will be welcome to attend information sessions or to enroll their children in RIte Care, but will not be required to enroll them until the month in which their geographic area is targeted. For example, as forty percent of the children in the target population have siblings in RIte Care, these families have experience with RIte Care and may wish to enroll their child in the program earlier.

Based upon the lessons learned from other States, Rhode Island believes that this phased enrollment will help assure provider continuity and a seamless transition to mandatory managed care enrollment for the target population.

The State plans to enroll the target population using a modified version of its current enrollment process, with additional steps and longer timeframes. Each RIte Care enrollee selects a Health

[10] In the past 16 months, 537 children have been disenrolled due to becoming eligible as SSI, Katie Beckett or adoption subsidy.

[11] As noted above, this includes approximately 8,700 children. It is projected that about 5,000 of these children do not have other insurance.

Plan and a Primary Care Provider (PCP).[12] The PCP provides a "medical home" for each enrollee. As with the rest of RIte Care, individuals in the target group will be offered provider information to facilitate their decision-making. Also as is currently the case in RIte Care, individuals will be able to call either the RIte Care Info Line (available in English and Spanish) or the Health Plans' customer service departments to ask questions and obtain additional information. Family Resource Counselors (FRCs) at some health centers and hospitals will also continue to be available to assist individuals in the enrollment process. Finally, the CEDARR Family Centers and advocacy organizations within the State will also be available to assist the individuals.

One way in which DHS anticipates that the enrollment process differs for the target population is the longer period of time allotted for choosing a Health Plan and PCP. In addition, once the family makes a choice, the Plan will have 45 days to conduct a health assessment screening and to identify the child's care needs, providers, and any other issues that might require attention. This will include verification of a selection of a primary care provider. RIte Care enrollment will commence for the child on the 45th day after the Health Plan is selected or assigned, in the event that no choice of Health Plan is indicated.

Once initial enrollment into RIte Care is completed for the targeted children currently enrolled in fee-for-service Medicaid, DHS may reduce the period between notification and active enrollment. The DHS considers it important to provide enough time for Health Plans to conduct initial assessments and affiliated activities for new enrollees with special health care needs. During regular enrollment of new clients, a shorter time frame may be sufficient to conduct these activities.

To assure that individuals have the information necessary to understand what is planned and to make an informed decision, the State will adapt current RIte Care enrollment materials as well as the *Rhode Island Medical Assistance Program Welcome Kit For Your Child with Special Needs*. As standard practice when developing RIte Care informational materials, the RIte Care Consumer Advisory Council will be involved in the process.[13]

3.3.5 Ensuring Health Plan Choice and Auto-Assignment

One of the most important differences in the enrollment process for the target population and the general RIte Care population is that for children in the target population, families that do not choose a Health Plan will have a different process to be assigned to a plan.

The State's primary goal is for families to have active plan selection. The State will encourage families to make an informed choice of the Health Plan that represents the best choice for the individual. Efforts will include:

- Concentration of information sessions in one region at a time;
- Communication via letters and the DHS website;

[12] For children with special health care needs, the State is underscoring the primary care physician's coordinating function. This is in addition to the PCP's primary care role for other RIte Care enrollees.

[13] Enrollment and eligibility materials for RIte Care are in both English and Spanish. Health Plan Member Handbooks are in additional languages, as required by the RIte Care Health Plan Contract depending on the numbers whose primary language is not English.

- Collateral efforts by advocacy organizations; and
- Enrollment information through Rhode Island Medicaid's fiscal intermediary.

To assist families in selecting a Health Plan, DHS will send each child's family a package that includes enrollment materials, information on the Health Plans, and a schedule of information meetings. The State recognizes that in some cases choosing a Health Plan will not be easy, particularly in those instances where the individual's providers may be split between different Health Plan networks. However, the State believes it exceedingly important to the health and well-being of the recipients (and their families) that a choice be made by them, not for them.

When a family does not choose a Health Plan for their child, the State will select a Health Plan. If the child has a family member in RIte Care, the child will be enrolled in the plan in which the family member is enrolled. For children without a family member in RIte Care , the child's file will be reviewed to determine if he or she was ever previously enrolled in RIte Care. Children with previous enrollment in RIte Care will be re-enrolled in the Health Plan the child was in before. In cases where the above methods are not available, a plan will be selected based on best fit between the child and the Health Plan. After plan assignment is made, the family may change plans at any point during the first 90 days of enrollment, as well as annually during plan enrollment.

3.3.6 Primary Care Provider Selection

Every effort will be made to ensure a PCP is selected during the 45 days between Health Plan notification and the effective date of enrollment, so that the Health Plan can verify the PCP selection with the family. If, despite efforts this does not occur, the Health Plan will make a PCP assignment for the effective date of enrollment. This will be consistent with current RIte Care protocols. The Health Plan will review its files to see if the child who has not selected a PCP has a sibling in the Health Plan. If the child's sibling is a Health Plan member, this PCP will be used for the child. If the child does not have a sibling in the Health Plan but has previously been a member of the Plan, the child's previous PCP can be used as the initial PCP. The State will also utilize any information participating Plans have about a child's PCP to assist families in making a decision.

In cases where no prior child or family information is available to guide assignment, a PCP will be selected based on geographic proximity. The child and family will be informed in writing of the assignment, and will be encouraged to contact the Health Plan if they wish to make a different choice. The Health Plan's welcome call to the family will also address this issue. As with other RIte Care enrollees, children with special health care needs enrolled in RIte Care will be encouraged to select a PCP and will be permitted to change PCP upon request.

The DHS anticipates that during the 45 days between when DHS notifies the Health Plan that a child has chosen the Plan, and when the child's RIte Care enrollment becomes active, the Health Plan will conduct several activities that will facilitate the child's transition to managed care. During the 45 day-period, the child's Health Plan will conduct an initial health needs screening. This "health needs assessment" will be used to identify providers and service needs and to refer families to other service providers/suppliers, when appropriate. This includes selection or verification of a PCP.

The Health Plan's screening will also trigger a referral to the CEDARR Family Center,[14] where further evaluation and care planning can occur as needed. Although actual use of a CEDARR Family Center is voluntary, DHS wants to ensure that all families are aware of the CEDARR Family Centers and feel able to access their services as needed.

3.3.7 Identification of Special Needs and Planning

The length of time between Health Plan selection or assignment and the active plan enrollment for the child with special needs will be longer than is the case for RIte Care enrollees in general. For this group, 45 days is the set period prior to the date of active enrollment in the Health Plan. This will give the Health Plan sufficient time to contact the family to identify the child's special needs and to ensure continuing care arrangements as needed, particularly where prior authorization procedures apply.

Upon notification of a child's enrollment, RIte Care plans are presently required to mail a welcome packet with information regarding the Health Plan and member rights and responsibilities. Health Plans also make a welcome call to enrollees with specific topics addressed in the script, such as confirmation or change of the member's PCP.

For children enrolled under this initiative, the Health Plans will have additional requirements tied to these activities, such as requirements related to written member materials dissemination and direct telephone contact with the family. A critical focus will be the identification of special needs in order to determine the need for other activities. For example, as part of the welcome call, the Health Plan will be required to conduct an initial screening to determine special health needs and critical ongoing relationships with providers and to coordinate appropriate arrangements for needed care.[15] For some children, special need does not mean an ongoing illness or treatment episode. Thus, care patterns will be fairly stable and the need for ongoing active interventions by the Health Plan to coordinate the transition may be fairly minor. In other cases where specific indicators or levels of need are identified in the screenings, the CEDARR Family Centers will also play a key role. For all children with needs at specified thresholds, the Health Plan will be required to make a direct and facilitated referral to a CEDARR Family Center.

3.3.8 Disenrollment from a Health Plan

Medicaid-eligible children with special health care needs will not be permitted to disenroll from a Health Plan back into fee-for-service unless certain criteria are met. This exceptions policy is currently in development. However, any Medicaid-eligible child may change Health Plans at will within the first ninety days of enrollment. After that, any Medicaid-eligible child will be able to change Health Plans "for cause" as determined and approved by DHS. In addition, as is current RIte Care policy, there will be an annual open enrollment period during which any enrollee may change Health Plans for any reason.

[14] Currently, over 500 children have utilized CEDARR Family Centers. For more information on CEDARR Family Centers, see Attachment A.

[15] The screening protocol to be used must be approved by DHS.

3.3.9 Re-enrollment in Instances of Lost and Re-gained Medicaid Eligibility

Medicaid eligibility is fairly stable for children with special health care needs. Over 75 percent of SSI and Katie Beckett eligible children were eligible for the entire year in 2001. This percentage reflects significant new enrollment during the year, as few children with special needs lose Medicaid eligibility during the year. For adoption subsidy children, ongoing Medicaid eligibility to age 21 is an element of the adoption contract between the State and adoptive parents. The incidence of re-enrollment upon lost and re-gained eligibility is expected to be fairly low; when this does occur, children will be re-enrolled in the Health Plan they were in previously, unless the family indicates a choice of plan at re-enrollment.

3.4 Provider and Specialist Capacity

The State has performed several tasks in order to come to grips with the provider network needs of children with special health care needs. The State reviewed the experience of other States as well as the various technical assistance materials that have been developed to guide the States in their network considerations for children with special health care needs.[16] These materials have provided the State with a starting point from which to investigate network needs. Two key issues raised by these materials are how to improve choice of providers and assure continuing access to current providers.

These issues have guided the Department's efforts to ensure that provider networks are as expansive as possible and include not only the providers currently used by children with special health care needs, but also include other providers that these children may not have been able to access through fee-for-service Medicaid. Our approach is based on the RIte Care experience since 1994, including DHS' efforts to ensure care coordination and access for the population of foster care children enrolled in Fiscal Year 2001.

The DHS reviewed Medicaid fee-for-service claims data for the target population in order to compare providers used by the children in Medicaid fee-for-service with the RIte Care Health Plans' current provider networks. The large majority of providers used currently by children with special health care needs are already in RIte Care Health Plan networks. Although this represents a large pool of providers experienced in working with children with special health care needs, DHS is currently working with families, stakeholders and Health Plans to identify possible network gaps and conduct provider outreach to further strengthen the Health Plan networks by recruiting additional providers.

The RIte Care Health Plans' networks are larger than is the pool of providers who accept Medicaid reimbursement for fee-for-service clients. As a result, enrolling in RIte Care will increase the number of providers available to the children in the target population. DHS is

[16] Among the materials reviewed are the following: Felt-Lisk, S., J. Mittler, and A. Cassidy. *Ensuring Special Needs Populations' Access to Providers in Managed Care Networks, A Technical Assistance and Self-Assessment Tool for State Medicaid Agencies*, Center for Health Care Strategies, Inc., January 2001. Institute for Child Health Policy. *Evaluating Managed Care Plans for Child with Special Health Care Needs: A Purchaser's Tool*, undated. Family Voices. *How Will Children with Special Health Care Needs Fare in Managed Care? Questions To Ask and Answer*, undated

working with the Health Plans to further increase the number of providers who participate in their networks.

To complement the internal review of provider lists, family participants in the stakeholder process have provided the names of providers who render services to their children with special health care needs, including individual practitioners, groups, institutions, agencies, and suppliers. This information has been passed on the RIte Care Health Plans for potential inclusion in their provider networks.

As part of the purchasing process, the Health Plans will be required to delineate their networks for children with special health care needs. To meet the diverse health care needs of the children to be enrolled in RIte Care, the Health Plans will need to: (1) include providers who practice outside Rhode Island in their networks (especially those in the bordering States – Connecticut and Massachusetts); and/or (2) allow children to retain established relationships with non-network providers. When foster care children were enrolled in RIte Care, the Health Plan worked with DHS to ensure that children could still see their providers who were not already Health Plan participating providers. The Health Plan reached out to providers to make them participating providers, and made allowances for historic providers when those individuals were not Health Plan providers.

RIte Care will offer allow a specialist serve as a child's PCP at the family's request, as long as the specialist can meet the requirements for a PCP as specified in the Health Plan contracts. The State realizes that specialist physicians often have an in-depth and ongoing relationship with a child that is very useful for identifying, planning, and coordinating the services that the child may require.

3.5 Coordination

3.5.1 Timely and Comprehensive Assessment of Each Child's Health Care Needs

As noted above, the State will require that within 45 days of being notified that a child is enrolling in the Health Plan, the Plan conduct an initial screening to identify special health needs. This screening must take place prior to the actual effective date of enrollment in the Plan. Based on the specific circumstances, this screening will lead to specific follow up care coordination activities within the plan and/or referral to and coordination with CEDARR Family Centers.

3.5.2 Care Coordination Services

Each Health Plan will be required to designate a Children with Special Health Care Needs Coordinator (Coordinator). The Coordinator will be a resource for enrollees, their parents, guardians, and adult caretakers and providers in obtaining needed services for children. Section 2.07 of current RIte Care Health Plan contracts requires "coordination with out-of-plan services and other health/social services available to members." This includes such services as special education, Early Intervention, WIC, and lead services. The State plans to modify the existing language in this section to incorporate specific references to the State Title V program as needed. The State will be guided in this and any other contractual changes by *Optional Purchasing Specifications: Medicaid Managed Care for Children With Special Health Care Needs*.

In enrolling children with special health care needs into RIte Care, the State will also draw directly on the system strengths developed through CEDARR Family Centers. The proposed enrollment of the target population into RIte Care builds on four years of work focused on children with special health care needs. Since 1998 the State has been actively engaged with stakeholders to identify critical needs of children with special health care needs and their families. The development of CEDARR Family Centers and the planning for this waiver amendment have been guided by these experiences. The CEDARR Family Centers have developed special expertise in comprehensive needs assessments, development of care plans for children and their families, systems navigation and services integration across often otherwise fragmented service and support systems.

The CEDARR Family Centers have engaged with approximately 500 children and families to date. On an ongoing basis, the Health Plan Coordinator will be required to work collaboratively with CEDARR Family Centers to develop, implement and monitor comprehensive care plans for children and their families which maximize services coordination and access to appropriate care.

3.6 Quality of Care

3.6.1 Performance Measures for Children with Special Health Care Needs

RIte Care already has a well-developed and nationally recognized research and evaluation component. Performance measures for children with special health care needs will build on this platform. Any performance measurement should be within the context of the following goals for this waiver amendment:

- Improve access to and coordination of care for Medicaid-eligible children with special health care needs;
- Improve the appropriateness of utilization of health care services by Medicaid-eligible children with special health care needs;
- Increase the level of consumer satisfaction with services available to Medicaid-eligible children with special health care needs;
- Improve health outcomes for Medicaid-eligible children with special health care needs; and
- Contain the growth of costs of serving Medicaid-eligible children with special health care needs (e.g., through reduced hospital days and emergency department visits).

The RIte Care Research and Evaluation Program will also incorporate key indicators for children with special health care needs. Key indicators will include selection of a PCP, completion of an assessment within 45 days of the date the Health Plan is notified that the child will be enrolled in the Health Plan, and coordination with CEDARR Family Centers. These indicators will be in addition to those administrative, access, and clinical indicators already in place for the State's innovative Performance Incentive Program, where the Health Plans are financially rewarded for

attainment of specific goals. Other performance measures specific to children with special health care needs may also evolve over time, based principally on consumer satisfaction surveys and complaints.

The State will remain mindful that evaluating the above goals and monitoring Health Plan compliance with contractual requirements pertaining to children with special health care needs will require distinct focus and attention.

3.6.2 Performance Improvements Projects to Address Issues for Children with Special Health Care Needs

Section 2.12.03.03 of the current RIte Care Health Plan Contracts requires both a written quality assurance plan and that each Health Plan conduct "at least three quality improvement studies annually directed at the needs of the RIte Care enrolled population." The State will consider amending this section to require that one of the three annual projects focuses on Medicaid-eligible children with special health care needs. In addition, over time, there may be other projects or special initiatives developed as deemed warranted by the results of ongoing monitoring and research and evaluation activities.

The three RIte Care-participating Health Plans are, as required by contract provisions, all licensed health maintenance organizations (HMOs). This also means that, as required by State law, each Health Plan is accredited by the National Committee for Quality Assurance (NCQA). As such, the plans must fulfill all of NCQA's requirements pertaining to quality assessment and improvement projects. Two of the Health Plans are also Medicare+Choice participating plans, which has another set of quality improvement requirements.

3.7 Other Policy Guidance

The State has received no other policy guidance from CMS to date relevant to children with special health care needs. As there is no other place within this format to consider benefits and cost-sharing, the State discusses these topics here. The benefits are the same as are available to the other children enrolled in RIte Care. Entry into RIte Care will not change the available benefits for children with special health care needs.

For the currently enrolled RIte Care population, enrollees with family income above 150 percent of the Federal poverty level must contribute to the cost of coverage. However, children in the target population for this Waiver Amendment will not be subject to the cost-sharing provisions required for the other RIte Care covered groups.

3.8 Payment Methodology

3.8.1 Methodology for Paying Health Plans

The State plans to work with the Health Plans to determine shared risk for this population. Options for financial arrangements with health plans are under review; it is essential that incentives for plans be appropriately aligned. Risk corridors and/or risk adjusters may be considered.

The State has undertaken a preliminary review of various risk adjustment methodologies that have been used or considered for children with special health care needs for potential applicability. [17] The State will use historical fee-for-service data for the waiver population, as well as encounter data (after children are enrolled) and Health Plan-specific utilization and cost data to determine what would work best in and be most equitable for all parties. Given that cost containment is only one goal motivating this Waiver Amendment Request (as with the rest of RIte Care), cost containment (including any at-risk arrangements) must be balanced against the other goals of access, quality, consumer satisfaction, and health outcomes. The State will approach at-risk arrangements including use of any risk corridors and/or risk adjustors prudently and deliberately.

3.9 Plan Monitoring

3.9.1 Process for Monitoring for Access to Services, Quality of Care, Coordination of Care, and Enrollee Satisfaction

From RIte Care's implementation in 1994, the State has had a well-developed program for monitoring both Health Plan contract compliance and performance and overall RIte Care performance. This has included annual consumer satisfaction surveys, on-site Health Plan reviews, clinical focused studies, review of complaint, grievance, and appeals data, special access studies, analysis and use of encounter data, collaborative studies (e.g., with Brown University), and Health Plan-required reports. In addition, DHS (and contractor) staff have and continue to meet with Health Plans on a regular basis, the RIte Care Consumer Advisory Council meets regularly, and DHS (and contractor) staff have and continue to convene special work groups composed of staff of other State agencies, advocates, Health Plans, and others as needed to address areas of concern (e.g., lead poisoning).

The State plans to continue these activities to address access, quality, care coordination, and enrollee satisfaction, remaining mindful that monitoring Health Plan compliance with contractual requirements pertaining to children with special health care needs requires distinct focus and attention. Each of these areas will be addressed as follows:

- **Access** – Access to services will be monitored principally through analysis of quarterly complaint, grievance, and appeal data, the annual Member Satisfaction Survey, and pre- and post-waiver amendment analysis of service utilization. Special access studies may be undertaken as circumstances may dictate.

- **Quality of care** – Quality of care will be monitored through the Performance Incentive System, mandated quality improvement projects, analysis of quarterly complaint, grievance, and appeal data, the annual Member Satisfaction Survey, and pre- and post-waiver amendment analysis of service utilization. Clinical focused studies or other special studies may be undertaken, as circumstances dictate.

[17] See, for example: Shenkman, E.A. and J.R. Breiner. *Characteristics of Risk Adjustment Systems*, Working Paper Series, #2, Division of Child Health Services Research and Evaluation, Institute of Child Health Policy, University of Florida, January 2001.

- **Care coordination** – Care coordination will be monitored through oversight of the initial assessment of new enrollees, follow-up care coordination activities, referrals to CEDARR Family Centers, evidence of collaborative working relationships with CEDARR Family Centers, analysis of quarterly complaint, grievance, and appeal data, the annual Member Satisfaction Survey, and pre- and post-waiver amendment analysis of service utilization. Special studies of care coordination may be undertaken, as circumstances dictate.

- **Enrollee satisfaction** – Enrollee satisfaction will be monitored principally through the annual Member Satisfaction Survey, analysis of quarterly complaint, grievance, and appeal data, and requests for changes of Health Plans and/or PCPs.

Children with special health care needs will be a separate and distinct sub-sample within the annual Member Satisfaction Survey, with information on this population analyzed separately. This will include comparisons with available benchmarks for children with special health care needs.[18]

As with all of RIte Care, consumer and stakeholder feedback in any form, whether part of the above activities or in another form, will be welcome and assessed.

3.9.2 Compliance with ADA Access Requirements for Enrollees with Physical Disabilities

RIte Care Health Plan Contracts already require compliance with the American with Disabilities Act (ADA). Review of Health Plan-proposed provider networks will assure that these requirements are met.

3.9.3 What Constitutes Medically Necessary Services

The definition of medical necessity in the RIte Care Health Plan Contracts, effective July 1, 1998, is already expansive:

> The term 'medical necessity' or 'medically necessary services' means medical, surgical, or other services required for the prevention, diagnosis, cure, or treatment of a health related condition including such services necessary to prevent a detrimental change in either medical or mental health status. Medically necessary services must be provided in the most cost effective and appropriate setting and shall not be provided for the convenience of the member or service provider.

The State believes this definition, which is in place for all Rhode Island Medicaid, is sufficient to ensure each child's needs will be met including those to achieve age-appropriate growth and development.[19]

The existing RIte Care Health Plan contracts address timeliness of authorizing services and timeliness of appeals. The State monitors the former through on-site reviews, the annual Member Satisfaction Survey, and the analysis of quarterly complaint, grievance, and appeals data. The State monitors the latter through analysis of quarterly complaint, grievance, and

[18] Griffin, J. *Health Care Needs of Children with Disabilities on Medicaid: Results of Caregiver Survey Final Report*, MCH Evaluation, Inc., June 8, 1998.
[19] This definition was crafted to incorporate EPSDT considerations.

appeal data. The Rhode Island Department of Health (HEALTH), with its statutory authority with respect to utilization review, also monitors timeliness of appeals.

3.9.4 Process for Monitoring Service Authorization Policies

Monitoring of service authorization policies has generally been conducted by reviewing and assessing internal Health Plan data during on-site Health Plan reviews. In addition, the annual Member Satisfaction Survey, analysis of quarterly complaint, grievance, and appeals data, and special access studies have also been used to assess compliance with contractual requirements. These methods will continue to be used. Due to its statutory authority in this area, HEALTH performs separate and distinct oversight in this area.

4.0 Revenue Neutrality

The Rhode Island Department of Human Services (DHS) is using the most current and complete data to develop budget projections for the Children with Special Health Care Needs. The projection uses date of service to accurately reflect utilization and expenses for the time period of this analysis. The populations included in the analysis are: those not yet twenty-one years of age, who are in Adoption Subsidy, "Katie Beckett" children and children eligible for Supplemental Security Income (SSI). In the analysis, DHS did not include children under age 21 who are in nursing homes or identified as participating in a special waiver managed by the Department of Mental Health, Retardation and Hospitals (MHRH).

The time period used for the development of this information uses calendar year 2000 and 2001 to assure the use of claims experience with the greatest completion factor using two calendar years should minimize any utilization that might be affected by seasonality. Using these parameters, the number of individuals in calendar year 2000 was 8,998 and 8,017 in calendar year 2001.

Using the claims experience for these populations in calendar years 2000 and 2001. The State is forecasting a per capita expense for each year through calendar year 2006. The scope of services used for this forecast includes ONLY those services, except for Neonatal Intensive Care Services (NICU), which will be provided in plan. The scope of benefits is the same as those benefits required under the 1115 waiver for other RIte Care eligible populations.

The information on the enclosed spreadsheets uses the following definitions:

1. Inpatient: includes all hospital inpatient services: medical, surgical or psychiatric

2. Inpatient – NICU - Out of Plan: includes services provided to those infants receiving intensive hospital based services immediately following birth. NICU services are paid directly by the state in a "carve-out" arrangement.

3. Outpatient In Plan: includes all other hospital-based services: Emergency room, imaging or radiology services, ancillary services, hospital based physical therapy or other therapies, ambulatory surgery (same day) procedures.

4. Professional – In Plan: includes all physician services (inpatient and office based), durable medical equipment and supplies.

5. Pharmacy: all medications prescribed for an individual by a physician or other license practitioner, including certain over the counter medications.

6. Intensive Community Based Services – those services and supplies including private duty nursing to maintain technology dependant children in home settings.

7. Behavioral Services: includes a full continuum of mental health and substance services and related rehabilitative services that are provided in a community setting.

8. Early Intervention: Children, ages 1 month to 36 months, are eligible for services that will support growth and development of those children identified with a physical or mental health condition that will delay ordinary growth and development.

In its analyses of these expenditures and forecasting those expenditures through 2006, the Department is proposing conservative estimates drawing on the available claims data, the experience within RIte Care and reasonable forecasts of market trends. The specific trends that the Department shows going forward are: 9.7% (2003); 10.2% (2004); 10.7% (2005) and 11.3% (2006).

Children With Special Health Care Needs
Expenditures Per Eligible Per Month By Category Of Service (Fee-For-Service Expenditures)

	Year of service	2000	2001	2002	2003	2004	2005	2006
Category	**Service**							
Inpatient	Inpatient	$285.05	$289.80	$301.39	$313.45	$325.99	$339.03	$352.59
	Inpatient - NICU - Out of Plan	$49.60	$51.43	$53.33	$55.30	$57.34	$59.46	$61.65
	Total Inpatient	**$334.65**	**$341.23**	**$354.72**	**$368.75**	**$383.33**	**$398.48**	**$414.24**
Outpatient	Outpatient - InPlan	$44.87	$50.79	$58.41	$67.17	$77.25	$88.83	$102.16
Professional	Professional - InPlan*	$58.31	$66.70	$76.71	$88.21	$101.44	$116.66	$134.16
	Pharmacy	$39.64	$52.31	$65.39	$81.74	$102.17	$127.71	$159.64
	Transportation	$2.44	$2.91	$3.06	$3.21	$3.37	$3.54	$3.71
	Total Outpatient, Professional & Other	**$145.27**	**$172.71**	**$203.56**	**$240.33**	**$284.23**	**$336.74**	**$399.67**
Special - Professional	Intensive Community Based Services**	$32.99	$44.48	$53.38	$64.05	$76.86	$92.23	$110.68
	Behavioral Health Services ***	$60.55	$61.44	$65.97	$70.86	$76.12	$81.78	$87.88
	Early Intervention	$8.13	$8.13	$8.45	$8.79	$9.14	$9.51	$9.89
	Total Special - Professional	**$101.67**	**$114.05**	**$127.80**	**$143.70**	**$162.12**	**$183.52**	**$208.45**
	Total Revenue Neutral Cost	**$581.58**	**$627.99**	**$686.08**	**$752.77**	**$829.67**	**$918.74**	**$1,022.36**

* Includes durable medical equipment and lab services.
** Services primarily for technology dependent children
*** Includes substance abuse rehab and comprehensive intensive services

RIte Care Enrollment for Children With Special Health Care Needs

Attachment: CEDARR Family Centers

Rhode Island's CEDARR Family Centers

The CEDARR Family Centers are now open and available for serving children with special health care needs. CEDARR stands for **C**omprehensive, **E**valuation, **D**iagnosis, **A**ssessment, **R**eferral and **R**e-evaluation – a one-stop source of information for Rhode Island families. CEDARR Family Centers can help children with special health care needs and their families with their need for information, professional assessment, specialty clinical evaluation, care planning, coordination of services, and ongoing referral assistance and support.

CEDARR Family Centers

About Families CEDARR Family Center
32 Branch Avenue
Providence, RI 02904
(401) 331-2700

Family Solutions CEDARR
134 Thurbers Avenue, Suite 102
Providence, RI 02905
(401) 461-4351 or (800) 640-7283

Families First CEDARR Center
Hasbro Children's Hospital
593 Eddy Street, Rm. 120
Providence, RI 02903
(401) 444-7703

What's unique about CEDARR Family Centers?

- **Family-Centered Care**
- **Family Service Coordinators** are there to serve you. Each CEDARR Family Center will have Family Service Coordinators that can help you get information, services and referrals.
- **Coordination of Care**
  with your child's doctor, with your child's school, with other providers
- **Services available statewide**

CEDARR Family Centers can provide:

Basic services and supports & specialty clinical evaluation and coordination of services for children with a range of conditions. Examples may include:

- Autism and related disorders
- Behavioral health
- Technology dependent care
- Severe medical or physical disabilities
- Developmental disabilities

CEDARR Family Centers can also serve children who do not yet have a diagnosis, but whose parents have identified a problem.

Who can get services at a CEDARR Family Center?

All children and their families can get services

How much does it cost ?

CEDARR services can be paid for by your health plan, the Medical Assistance Program, or by the family, depending on your situation…

- If your child has employer-sponsored health insurance, check with your health plan to see if CEDARR services are covered.
- If your child is eligible for Medical Assistance, the CEDARR Family Centers will bill the Medical Assistance Program for services.
- For those without health insurance or if a health plan does not cover CEDARR services, payment arrangements can be made with the CEDARR Family Center for services.

How can I get Medical Assistance for my child?

There are four ways that children may become eligible for *Medical Assistance* coverage:

Supplemental Security Income (SSI)

If a child is eligible for Supplemental Security benefits because of a disability, then that child is also eligible to receive Medical Assistance. To see if your child may be eligible, call (800)772-1213.

Katie Beckett

Certain children under the age of 18 may be eligible for Medical Assistance if they have a disability and live at home. Only the child's income and resources (not their parents') are used to determine eligibility. This enables children with disabilities to be cared for at home instead of in an institution.

RIte Care

RIte Care, Rhode Island's health insurance program for children and families provides comprehensive health care through enrollment in one of three participating Health Plans (United Healthcare, Neighborhood Health Plan and Blue CHiP). Eligibility is based on income and family size. A family's resources, such as a house or a car, are not used to determine eligibility. RIte Care is part of Rhode Island's Medical Assistance Program.

RIte Share

Children and families who are eligible for Medical Assistance (based on income and family size) and whose employer offers an approved health insurance plan may be eligible for the RIte Share Premium Assistance Program. With RIte Share, families enroll in their employer's health insurance plan. RIte Share will pay for all or part of the health insurance premium for family coverage.

For more information, call:

RI Department of Human Services'
Center for Child and Family Health Info Line
Monday- Friday 8:30 a.m.- 4:00 p.m.

401-462-1300 English **401-462-3363** TTY (hearing impaired)
401-462-1500 Spanish

Funded and administered through the Department of Human Services. Other participating agencies include: the Department of Health, the Department of Children, Youth and Families, the Department of Education and the Department of Mental Health, Retardation and Hospitals.

CEDARR Family Center Services

The following are the services that may be provided by a CEDARR Family Center to children with special health care needs and their families:

Initial Family Contact

Initial Family Contact with a CEDARR Family Center (CFC) can range from the routine inquiry of a family looking for basic information, to the family seeking additional in-depth evaluations and a coordinated Family Care Plan (FCP). In many cases, the Initial Family Contact will progress into and become part of the Initial Family Assessment. Intake appointments must be scheduled within 14 calendar days of initial request for routine cases. In the event of a crisis or urgent situation, the CFC is expected to respond and provide appropriate Clinical Triage services.

Initial Family Assessment and Basic Services and Supports

The Initial Family Assessment (IFA), including the Initial Family Contact and Basic Services and Supports, comprise the services available to a family upon entry into a CEDARR Family Center. These services may be provided over the course of one or more visits with the child and family. Visits may take place in the home, a community setting or at the CEDARR Family Center, as determined by the family and the CEDARR Family Center.

Basic Services and Supports

Basic services and supports provided by the CEDARR Family Center include:

- The provision of Special Needs Resource Information: In a culturally competent manner, CFCs will have the necessary expertise to inform families and to enable families to inform themselves about specific disorders, prognosis, research findings, treatment and provider options.

- System Mapping and Navigation: Tailored to the needs of the child and family, the CFC shall fully inform the family of the whole system of support, services, assistance and legal rights available to children with special health care needs and their families. The family shall receive assistance in creating their own personal map to navigate the system. This includes understanding eligibility requirements, service coverage and related policies of existing programs, accessing insurance coverage, and interagency coordination issues.

- Resource Identification: The CFC shall help families identify the resources that are available beyond the scope of Medicaid. These resources shall include, but are not limited to: parents, family members, service providers, grants, social programs, support groups, funding options, recreation and school-based opportunities. A core objective is that families are informed of resources closest to home that are least restrictive and are keyed toward integration in the home and the community.

- Eligibility assessment and application assistance: The CEDARR Family Center may assist a family in determining potential eligibility for various programs e.g. Medicaid, Early

Intervention, Special Education, Local Coordinating Councils, and if desired by the family, will assist the family in making an application.

- Peer Family Support and Guidance: Peer family support and guidance is accomplished by linking parents with peers in one-to-one meetings or in family support group meetings. CEDARR Family Centers shall develop formal written agreements with appropriate parent support and information centers to enhance their efforts to provide basic services and supports.

Initial Family Assessment

The goal of the IFA is to develop a working profile of the family that forms the foundation for the assessment. The assessment includes: an assessment of urgency; a developmental and diagnostic history (including physical health, behavioral health and cognitive development); an analysis of current interactions with the care system (pediatrician or other primary care provider); involvement with other programs (Early Intervention, RIte Care, SSI, Katie Becket, DCFY programs and school programs); family strengths, needs and supports; knowledge of or linkage with advocacy groups or professional associations; current insurance status and needs; and potential eligibility for various public programs or community supports.

Specialty Clinical Evaluation

The Initial Family Assessment may identify the necessity for an in-depth specialty clinical evaluation, assessment and diagnosis. The specialty clinical evaluation is performed by a CEDARR Family Center affiliated clinical specialist and is used to further inform the assessment and to guide the development of the Family Care Plan. Medicaid reimburses specialty clinical evaluations.

Treatment Consultation

Treatment consultation is designed to support the participation of the child's primary care physician (PCP) in the development and review of the Family Care Plan.

Family Care Plan (FCP) Development: The Family Care Plan is a comprehensive plan developed by the family and the CEDARR Family Center team of professionals designed to address the child's and family's needs for services and supports. As appropriate, the FCP may be developed in coordination with existing community resources, specifically Early Intervention Providers, Local Coordinating Councils and Local Education Agencies. The FCP can include Direct Service and Support Services and collateral support services. The FCP may include Family Care Coordination Assistance.

Family Care Coordination Assistance (FCCA)

Family Care Coordination Assistance incorporates a range of activities supportive of the initiation of the Family Care Plan as well as activities that promote the development of family empowerment and self-advocacy skills. It is a service that must be elected by the family. Family Care Coordination Assistance is time-limited (six months) but may reoccur during transition periods. Activities can include assistance to gain access to services identified in the FCP,

coordination and follow-up measures with the family regarding the FCP, and to achieve coordination across programs and funding sources, to strengthen family skills and knowledge of the system and the child's condition, family supports and linkages, and monitoring and re-evaluation of the FCP. The purpose of the FCCA relationship is to promote fully realized family independence.

Family Care Plan Review and Revision

Family Care Plans including direct services or Family Care Coordination Assistance must be reviewed at least every six months. At this point the assessment is updated to identify any changes that may have occurred, and to assess progress in meeting goals and obligations identified in the Family Care Plan, to develop a revised Family Care Plan, as appropriate. The Family Care Plan Review must be developed and signed by the child's parent(s) or authorized guardian.

Crisis Intervention Services

All Family Care Plans must specify what to do in a crisis so that there is an understanding and agreement by all involved parties. Direct service providers for Crisis Intervention must be specified in the Family Care Plan. Additionally, all CEDARR Family Centers are accessible 24 hours a day by phone so that any family or professional can ask for instructions on what to do in a crisis. The CEDARR Family Centers provide Clinical Triage and Crisis Follow-up Care Coordination. A licensed Master's level clinician must perform these services. Crisis follow-up Care Coordination must be provided and includes direct follow-up communication with clinical staff of the direct service provider of crisis intervention services, collaborative work with the family in determining next steps and arranging for community-based services as appropriate.